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1 **The performativity of numbers in illness management: the case of Swedish**
2 **Rheumatology**

3 **Anna Essen & Eivor Oborn**

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6
7 **ABSTRACT**

8 While there is a proliferation of numerical data in healthcare, little attention has been paid
9 to the role of numbers in constituting the healthcare reality they are intended to depict.

10 This study explores the performativity of numbers in the microlevel management of
11 rheumatoid disease. We draw on a study of patients' and physicians' use of the numbers
12 in the Swedish Rheumatology Quality Registry, conducted between 2009-2014. We show
13 how the numbers performed by constructing the disease across time, and by framing
14 action. The numerical performances influenced patients and physicians in different ways,
15 challenging the former to quantify embodied disease and the latter to subsume the disease
16 into one of many possible trajectory standards. Based on our findings, we provide a
17 model of the dynamic performativity of numbers in the on-going management of illness.
18 The model conceptualises how numbers generate new possibilities; by creating tension
19 and alignment they may open up new avenues for communication between patients and
20 physicians.

21 Key words: Sweden, quantification, quality registry, rheumatology, patient-reported-
22 outcome measures, performativity, patient-physician interaction, temporality

Research highlights

- Little is known about how numbers perform in illness management
- We show how numbers perform differently for physicians and patients
- Numbers constructed the disease across time and framed action
- Interaction between numbers, physicians and patients produced tension and alignment
- We contribute a new model of the dynamic performativity in illness management

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The Performativity of Numbers in Illness Management: The case of Swedish Rheumatology

INTRODUCTION

There is a proliferation of numerical data in health care systems, as well as a quantification in society more generally (Espeland and Stevens, 1998; 2008; Power, 1997). While a growing and interdisciplinary literature suggests that numbers tend to intervene in the reality they are intended to depict (e.g. Callon, 1998; Porter, 1995; Espeland and Sauder, 2007), such consequences have been little explored in the healthcare field. A few studies (Nicholls, 2013; Wallenburg et al. 2016) illustrate the disciplinary potential of numbers and numerical standards at system level. However, the question of how numbers may perform in the continuous and microlevel process of illness management has gone unacknowledged. Nonetheless, a range of different types of numbers are invading this context; for instance, numbers generated by laboratories, professionals' assessments, patients, algorithms and wearable sensors. The lack of empirical examination of how these different numbers do things other than reflecting reality in processes of illness management is problematic as it limits our understanding of the multiple agencies involved in shaping healthcare practices; how and why decisions are made and how we can avoid the potential risks that may be associated with illness quantification.

Against this background, the present study attempts to answer: How do numbers perform in the microlevel management of illness? We explore the performativity of the numerical data used in the patient-physician encounter in the Swedish rheumatology setting, drawing on a field-study conducted between 2009-2014. We found that numbers performed by constructing a boundary between disease and life across time, and by framing action. The numbers performed differently for patients and physicians across these performance arenas.

1 The interaction between patients, physicians and numbers further lead to tensions and
2 possible alignment between patients and physicians which we found to be generative in
3 managing illness, for example empowering the patient in new ways. Based on our findings,
4 we provide a conceptual model of the dynamic performativity in illness management that
5 extends the dominating portrayal of numerical performances in healthcare as static or
6 disciplinary.

7 **THE WORK OF NUMBERS BEYOND REFLECTING REALITY**

8 An interdisciplinary literature spanning history of science (e.g. Crosby, 1997; Porter, 1995)
9 sociology (e.g. Callon, 1998; Espeland and Stevens, 1998; 2008; Weber, 1978), and
10 organisational studies (Déjean et al. 2004; Leca and Naccache, 2006; Power, 1997) suggests
11 that numerical representations, measures and statistics tend to reshape the social world that
12 they are intended to depict. That is, numbers not only have instrumental consequences
13 (describing “reality”, making issues visible, and enabling “real” organizational evaluation and
14 improvement), they are also “performative” (Callon, 1998) as they actively *constitute* reality.
15 The section below highlights key aspects of performativity that have been discussed in
16 seminal pieces concerning the work of numbers. For more comprehensive sociological
17 reviews of the work of numbers, see e.g. Espeland and Stevens (1998; 2008).

18 As noted by Espeland and Stevens (1998:314), consequential uses of numbers typically entail
19 commensuration: “the transformation of different qualities into a common metric”.
20 Commensuration makes all entities measured bear a common relationship to each other. At
21 the same time it also distinguishes objects, by “assigning to each one a precise amount of
22 something that is measurably different from, or equal to, all others. Difference or similarity is
23 expressed as magnitude, as an interval on a metric, a precise matter of more or less”
24 (Espeland and Stevens, 1998:408). In this way, commensuration enables comparisons and

1 scaling of objects, which in turn create new relationships between objects: *uniting* objects by
2 making a priori separate things hold together, and *differentiating* objects by creating or
3 reinforcing boundaries between categories of people and things, which may generate
4 unintended effects (Espeland and Stevens, 2008).

5 The authority of numbers vis-a-vis other knowledge representations originates in the long and
6 evolving association between numbers and rationality and objectivity (Nussbaum 1986;
7 Weber 1978). Numerical commensuration fosters what has been referred to as mechanized
8 judgment (Leca and Naccache, 2006, cf mechanical objectivity (Porter, 1995)), which, in
9 contrast with judgement grounded in expert opinion and elite discretion, complies with
10 standardized rules about how to derive, manipulate and use numbers. According to Porter
11 (1995), the value of such rules is that they are impersonal, constraining, and limit personal
12 discretion when credibility or disinterestedness is suspect. Porter (1995) further argues that
13 the mechanical objectivity enabled by numbers tends to replace trust in persons with trust in
14 numbers.

15 As such, numbers can possess authority to a degree that they reduce the measured object to
16 its measurable dimensions (cf. Leca and Nacchache, 2006; Callon, 1998). This tendency thus
17 hides or pushes out non-measured qualities and variations, making only that which is
18 measured, perceived as “real”. Espeland and Sauder (2007) further highlight the potential of
19 measurement to make the object more *like* its measurement, concluding that numerical
20 representations tend to become self-fulfilling prophecies.

21 The above indicates that numbers can exert discipline on those they depict (e.g. Foucault,
22 1977). Numbers discipline as they can cause people to think and act differently, as they can
23 influence our ambitions and how we view ourselves. Further, as noted by Espeland and
24 Stevens (2008: 415), “quantification expands the comprehensibility and comparability of

social phenomena in ways that permit strict and dispersed surveillance.” An illustrative example of such forms of numerical governance is provided by Espeland and Sauder (2007), who show how rankings change how internal and external actors think about the field of legal education through processes of surveillance and normalization (Foucault, 1977). These new understandings of legal education, in turn, encourage schools to self-impose the discipline that rankings foster. Similarly, work in medical sociology has demonstrated the potential of numbers to shape what and who becomes eligible for participating in an evidence-based program (Wehrens and Bal, 2012) and the potential of numbers to foster simplified understandings of disease that fails to acknowledge intra-class variation (Nicholls, 2013).

The question remains, however, how the performative potential of numbers discussed above may play out in the on-going management of chronic illness, in relation to individual patients and physicians. It seems reasonable to assume that the authority and performativity of numbers may shift over time and that it may differ in relation to individuals with different roles. It is the aim of the present study to highlight such dynamics in the work of numbers in the microlevel management of chronic disease.

METHODS AND CASE CONTEXT

We use data from a revelatory context (Yin, 2009) in which patients and physicians use an extensive array of measures on a continuous basis: the treatment of rheumatoid arthritis (RA) in Sweden.

Empirical setting

We focus on the use of numbers in the Swedish Rheumatology Quality Registry (the registry), which was initiated by the Swedish Society for Rheumatologists in 1995. A group of rheumatologists and a representative from the Swedish patient association was involved in

selecting the variables initially included in the registry (see Essén and Lindblad, 2013). Today, rheumatologists use the registry for research purposes. They also use the registry as a decision-support system together with patients. The registry contains numerical data about physician prescriptions (drug dosages) and their outcomes. Outcomes include patient-reported outcomes (functional ability (HAQ)), joint count (JC28/66), pain (VAS), patient global health (PGH) and quality of life (EQ5D), lab-test results (CRP, SR), and physician reported assessments (JC28 and physicians' global). The DAS28 index score is automatically calculated when all variables are registered, based on an algorithm that adds and weighs several of the scores, including JC28, SR and PGH. Figure 1 below shows numbers as displayed on the physician's computer screen.

Insert figure 1 about here.

Sweden is a tax-funded system available to all residents. It therefore has different incentive structures than more market-based systems such as the US. Further, Swedish rheumatologists and patients used the registry on voluntary basis; use was not mandatory or tied to financial incentives. However, as data was increasingly made available to external parties, such as national health agencies who included some of the measures in national public performance reports, rheumatologists faced a growing expectation to use the registry (see Essén and Sauder, 2017).

Data generation

We use empirical material collected in a larger field-study of the development of the registry since 1995, performed between 2009-2014 and including 83 interviews and 15 observations (see Table 1). Ethics approval for research was obtained from the Stockholm Ethical Committee. Informed consent was sought from all participants by the first author. What emerged from the field-study was that the registry numbers (numbers) influenced the RA

patients and physicians in intended and unintended ways, which triggered us to explore this issue further. Interview questions relevant for the present study were: how do you use the data in the registry? Have you learned something new by using the data? Has using the data made you change the way you work/how you make sense of your disease? The questions were of an open-ended character in order to allow for unexpected issues to emerge. The interviews were recorded and transcribed in Swedish by the first author. The first author also conducted observations of the patient consultations at two clinics, paying attention to how patients and physicians or nurses used the data in situ. Notes were taken during and completed after each observation (Lofland et al. 2006).

Insert Table 1 here.

Data analysis

Given gaps in existing theory, we used a grounded theory approach including a three-step coding process (Corbin & Strauss, 2008). Field-notes and documentation were first reviewed to understand the context in which the numbers were used. Based on our aim to understand how numbers perform in the microlevel management of rheumatoid disease, the first author then conducted an open coding of interview transcripts and observational notes to identify different “roles” of the numbers, as exemplified in each of the columns in table 2 below. Both authors then engaged in axial coding, clustering codes into themes, presented in bold in table 2. Finally, we compared and contrasted themes, and related them to the literature on quantification, arriving at the categories in Table 2. We examined how these categories fit together to capture the dynamics we observed, illustrated in Table 2 and in figure 3. Note that the data analysis process was iterative rather than sequential; we repeatedly went back and forth between themes and categories.

Insert Table 2 about here.

The performativity of numbers in the microlevel management of rheumatoid arthritis

In the following analysis we examine the performative aspects of the numerical data in the registry (the numbers) in managing rheumatoid disease (RA) in Sweden. We show how the numbers performed differently for patients and physicians in 1) constructing the disease across time, and 2) framing action. Further, we found a dynamic interplay between the work of numbers, patients and physicians during patient meetings. In the second half of the analysis, we examine how numbers enabled tension and brought alignment between patients and physicians in their management of rheumatoid illness.

Constructing the disease across time

The numbers in the registry made the boundary between rheumatoid arthritis (RA) and ‘the rest of life’ visible and they made different dimensions of the disease commensurable. The visibility and commensurability constrained and enabled patients and physicians to construct the disease in relation to different temporal points of reference.

Patients’ perspective

Many patients who had suffered from RA for several years (up to 30 years) referred to their disease as a mystery with many ambiguous symptoms that they felt unable to fully understand let alone control. It was difficult to articulate whether or not they were getting better or worse; their lived experience was ephemeral and shifting. The registry disciplined patients by asking them to rate predefined dimensions of this experience, and according to standard scales and alternatives, as explained by one patient:

The questions [in the registry] are static. My issues change over time! Sometimes I have pain in my feet. Sometimes my skin is sore. Sometimes I am unbelievably tired... It is difficult to summarise this into a location on the VAS scale [asking about “overall” health status]...but I try (Patient #23, Male, 8 years of diagnosis).

1 The patients put in a lot of effort to comply with the numerical scoring system. Many patients
2 argued that it was worthwhile, because once in place and displayed on the screen, the
3 numbers disentangled their complex past into distinct and more manageable health
4 “dimensions”, such as pain and ability to perform daily chores, as seen in Fig 1. The
5 numerical descriptions constructed a historical reference point, which patients could use
6 when analysing their past illness. For example, in the quote below, a patient refers to how she
7 has been looking at her reported measures over the last 2 years to understand better whether
8 or not her disease is deteriorating.

9 *The last time I looked, it [self-reported HAQ] values had not changed during the past*
10 *2 years... in fact, most of my self-reported values: pain, quality of life and my global*
11 *assessment showed no signs of deterioration, which made me quite happy and it*
12 *confirmed my intuition. My medication is working well....Seeing the numbers made*
13 *me even more sure of this...*” (Patient #6, Female, 13 years of diagnosis).

14 Several patients also explained how the reducibility of numbers made it possible to draw a
15 boundary around the illness so as to set it apart from their wider life, as illustrated in the
16 following quote:

17 *When I ask myself: how have I been lately, I feel confused. I try to remember certain*
18 *events, for example, when we visited our friends, was I in pain then?... Was this*
19 *related to my RA or something else?... With [the numerical assessment of my RA] it*
20 *becomes more delimited, more related to the illness. [the set of numbers] enables me*
21 *to draw a line around the illness related symptoms* (Patient #2, Female, 4 years of
22 *diagnosis)..*

23 The patients were aware of the imperfectness of the numbers. Nevertheless, numbers
24 bounded patients’ past life experiences in a coherent framework that summarised their illness
25 as separated from their wider life, thus constructing the illness as manageable ‘dimensions’.

26 The numbers further connected patients’ past illness with the present in what patients felt was
27 a systematic, concrete way. The numbers provided traces of the illness that established the
28 disease progression in a comparable way. As expressed by one patient:

1 *I use the assessments to compare if my health is getting better or worse....I mean, I*
2 *don't need to look at the numbers to know how I am today. That, I feel. But in order to*
3 *make some kind of conclusion ...I need to compare with something, something more*
4 *than my memory (Patient #6, Female, 13 years of diagnosis).*

5
6 The numbers thus confirmed patients' lived experience of their illness and concretised its
7 temporal unfolding. This validation gave patients the assurance that their perceptions were
8 true.

9 *The last time I looked...most of my self-reported values...showed no signs of*
10 *deterioration, which made me quite happy and it confirmed my intuition. My*
11 *medication is working well....Seeing the numbers made me more sure of this (Patient*
12 *#10, Female, 6 years of diagnosis).*

13 In this way numbers provided patients with reassurance, communicating aspects of the illness
14 as "credible" so as to enable sensemaking.

15 Those life experiences that were not included on any of the scoring metrics became separated
16 from the illness. These experiences were more difficult to validate and affirm. For most
17 patients these aspects of living with the illness became personal, a part of 'life' rather than
18 part of the actual illness and were typically deemed less important to the medical
19 professional, though the boundary between the two was flexible.

20 21 *Physicians' perspective*

22 For physicians, the numbers provided a set of reference points against which they could
23 compare and evaluate their work. As noted by a physician, the numbers provided a sense of
24 consistency and control compared to the state before.

25 *Previously [before the registry], I tried to summarise the patient's state in the record*
26 *notes. The notes were often hard to compare over time and to use to make a*
27 *prognosis...and suddenly the patient was in a wheel chair without one really knowing*
28 *how that happened (Physician #1, Male, 19 years of experience).*

For physicians, numbers circumscribed their responsibility, their professional jurisdiction, thus creating a boundary between their responsibility and non-responsibility. For instance, a physicians mentioned that the numbers made the disease more manageable as the numbers articulated the dimensions that doctors were able to influence with their repertoire of tools:

The measures help me focus on the health symptoms that I can do something about. There are vast “disease-related” symptoms...patients often mention numerous ambiguous problems that they suffer from, and, while I sympathise with them, I cannot address everything. Like depression, I refer such patients to a psychologist instead... By showing that this is what we measure in the RA registry, this is what is considered “RA” symptoms according to research, this is the parameters that we use to evaluate new drugs, its easier for me to explain and justify to the patient –and myself!—why I focus on these rather than other symptoms. (Physician #43, Male, 8 years of experience).

Similar to patients, physicians did not believe that the numbers accurately described all dimensions of a patient’s health status, further pointing to flexibility in how the boundary between life and illness was established. Thus, all physicians emphasised the need to combine and corroborate several numerical values and their own assessment to establish whether or not the numerical values could be “trusted”. However, while being aware of the limitations of the numbers, the physicians found them helpful. The fragmentation of the illness into multiple metrics rendered the different dimensions of the disease comparable. The disease dimensions could then be analysed together to see if they corroborated a similar presentation, thereby rendering the *type* of illness knowable.

This more systematic way of analysing numbers helps me get an overall picture of what kind creature I am to deal with. Is it an aggressive or uncomplicated disease?... Some disease types don’t increase RA or CRP levels, some manifest in one or two joints, other types move around more. But based on an analysis of these values, it is easier to make predictions of its future trajectory, as patterns tend to be repeated (Physician #2, Female, 15 years of experience).

Physicians found the DAS28 index measure particularly relevant as it has been validated in numerous studies and shown to predict functional ability (HAQ) and joint destruction (X-ray progression). As such, the DAS28 worked to construct the nature of the disease in relation to

established illness trajectories. In the following quote a physician talks about how the DAS28 performed by revealing the trajectory of the disease:

DAS28 is a great shortcut to get a broad image of the patient's current and future overall health, as it is based on several dimensions, including also patients' self-reported global health. ..I use it as a confirmation of whether or not the patient is in a stable phase or in the middle of a flare ...this helps me to form an expectation of what's coming next (Physician #10, Male, 18 years of experience).

Many physicians indicated the numbers predicted 'the slope of the curve' and also identified where the patient was currently located on the slope; for instance, whether the patient was on the upward or downward phase of the theoretical slope. As seen in the image below, a physician drew this picture of the DAS28 curve during an interview, referring to how his major aim was to "cut" the curve as early as possible.

Insert (Figure 2) here

In summary, patients and physicians were aware of the limits of the numbers to accurately reflect all aspects of and the nature of the disease. Yet, the numbers worked to construct a boundary around the disease across time, rendering its past, present and future knowable.

Framing action

Numbers also shaped physicians' and patients' aspirations and what actions they deemed necessary. This role of numbers also played out differently among physicians and patients.

Framing physicians' action

The numbers shaped physicians' action plans by enabling field-level medical standards to become reducible to the patient at hand. Specific values in the registry could be compared to established standards of "active" and "inactive" disease and "low", "moderate", or "high" disease activity in the scientific literature. These standards were developed from numerous research trials that aggregated scores across a multitude of patients.

For instance, patients with a DAS28-score <3.2 were categorised as having low disease activity, and patients with >5.1 as having high illness activity. Two crucial groups were hence recognised, namely low scorers, which the registry system marked green, and high scorers marked red (>5.1) by the system. National performance monitoring of ‘red’ and ‘green’ patients was enabled through the reporting procedures of the registry, which produced statistics for comparing rheumatologists’ care across the Swedish counties.

Some physicians expressed that the comparability of patients’ numerical values with established categories made them more focused on action that would enable meeting certain categories or measurable goals, such as having as few of one’s patients’ as possible in the “red” category, as measured by DAS28. Some physicians argued that they now, with the availability of numerical data, adjusted drug dosages and tested different combinations of drugs more frequently in order to minimise “red patients” (reduce high DAS28 values).

The fact that the numbers constructed the illness as active to different degrees also communicated to the physician and wider system whether or not the patient was eligible for certain drugs and the attention associated with those drugs. BioMeds, an expensive form of medication, was available to patients having “severe” illness according to the medical guidelines. Physicians maintained that they were restricted from prescribing BioMeds to patients with low DAS28 scores, indicating that numbers can be used to justify non-prescription of expensive drugs as guideline adherence:

If a patient has great scores I am not inclined to prescribe biodrugs even if a patient may suggest this. These expensive drugs are not for mild cases. They are for the most severely ill patients. (Physician #42, Male, 9 years of experience).

Registry numbers worked further to place patients in one of the following categories: the “BioMed” group and those on “Other treatments”. Patients in the BioMed category (typically those with higher initial disease activity scores) were analysed more comprehensively than

other patients. For instance, biomed patients had a distinct set of diagrams that dominated the annual rheumatology registry report and the national public performance reports. The public comparisons of the numerical values of biomed patients disciplined physicians' attention and behaviour towards these patients. As argued by a physician:

The comparisons makes visible to what extent we [physicians] prescribe biomed to patients with severe illness as recommended, and to what extent our biomed patients exhibit significant health improvements...this makes one strive to follow the recommended actions and to reach the expected outcomes in this population more than before [without the numerical comparisons]. (Physician #3, Female, 8 years of experience).

Framing patients' action

Patients reacted differently to the numerical values that they and their physician had created. To some patients, being placed in a certain category signalled a need for action. For instance, being in the "red" category triggered self-management changes among some patients:

I was a bit surprised to see my [DAS28] value was red [high disease activity]. I got some new drugs but I was like, oh my god, maybe I should become a vegetarian after all...I have read that vegan diets can reduce inflammation. (Patient #10, Female, 6 years of diagnosis).

Other patients referred to similar ways in which they tried to make connections between "bad" numbers and their own lifestyle and everyday activities. For instance, patients usually reflected on whether they had been exercising too much or too little, if they had been too generous with the wine, or had been sleeping insufficiently. However, as the patients' behaviours outside the hospital were not measured in the system, the connections between patients' own actions and numerical outcomes were difficult to establish. Further, there were no medical guidelines recommending certain patient action responses to certain values. Thus rising numbers relegated patients' actions to a passive role, since the numbers had been separated from their wider life.

If my DAS28 is red, what can I do? I only have my diffuse experience to rely on. So I may think, OK I need to sleep better, which is easier said than done....Initially, I

1 *asked my doctor, is there anything I can do? ... But my doctor always gave me the*
2 *same ambiguous answer, that there is no evidence supporting a certain diet...so I end*
3 *up uncertain about what to do. (Patient #9, Female, 6 years of diagnosis).*

4 In summary, the distinction between patients who scored 4.9 and 5.1 may in reality be quite
5 minimal, yet the (standards surrounding the) numbers steered physicians' to provide such
6 patients with different treatments, and access to different levels of attention. In contrast, the
7 numerical values were more ambiguous about establishing patients' behaviour as most of
8 their arena of action was framed as outside the boundary of the 'illness'.

9 **Tensions created through the interplay of numbers, physicians and patients**

10 The work of registry numbers in constructing the disease across time and framing action
11 sometimes created tensions between patients and physicians. For example, some patients
12 perceived that the numbers took too large a role in managing their illness:

13 *My doctor seems less interested in my sleeping problems [not measured] than my*
14 *CRP/RF [measured], but for me, sleeping well is perhaps the most important thing. If*
15 *I sleep well, my overall health improves dramatically...But he seems to think sleep is*
16 *my own responsibility, not his (Patient #28, Male, 3 years of diagnosis).*

17 This aspect of the disciplinary influence of numbers was troubling to patients who suffered
18 from several, ambiguous symptoms that were not assessed numerically.

19 *I would like a leg surgery so I would love to have 'hard facts' about my leg*
20 *problems...But the system does not allow me to 'rate' my leg problems and thus*
21 *collect evidence about that... rather, when my doctor looks at my PER assessment, I*
22 *appear to be fine, while I'm not... perhaps as [my problems are]not included in the*
23 *system?...I try to bring this up but he doesn't seem to care (Patient #20, Female, 15*
24 *years of diagnosis).*

25 Further, some patients disagreed with the action plans that physicians derived from the
26 numerical scores. The numbers sometimes worked to steer the doctors' thinking away from
27 what the patient might have anticipated. For example, patients on occasion wanted biomed
28 drugs even when they were not deemed eligible by their numerical values:

1 *I would like to try the new [biomed] drugs, but my physician says they are not for me.*
2 *But I am in fact not well! They seem to think I am “well enough”, that I should “be*
3 *happy” with my “stable” condition. But I want to become better! I am still very*
4 *functionally limited (Patient #4, Female, 2 years of diagnosis).*

5 Tension was also generated as patients reacted to the way the numbers made physicians focus
6 on drug prescriptions inherent in standard packages of care. A specific score framed a
7 particular kind of action, based on an inferred cause, such as more aggressive disease.

8 *My physician always draws the conclusion that more drugs are needed if my scores*
9 *are bad. I don't want more drugs. I think the drugs cause, or at least worsen some of*
10 *my problems. ..I would like to know more about what I can do to prevent further*
11 *problems. If my doctor would have told me ten years ago that exercise is good then I*
12 *would have been far better off today. Now I have started to swim, it makes me feel*
13 *much better. On the other hand, sometimes I train too hard... But my physician seems*
14 *to see that as my private issue. (Patient #21, Male, 23 years of diagnosis)*

15 As numbers changed over time, for example got worse, tension arose in understanding the
16 possible causes. Whilst physicians generally linked the change in numbers to either the
17 treatment or the disease, patients were also concerned to understand how their wider life (e.g.
18 too much exercise) influenced the numbers. Having established a boundary between life and
19 disease, numbers worked to disconnect patient actions from disease outcomes.

20 In summary, the dynamic interaction between the agency of the numbers, patients and
21 physicians occasionally led to tension between the appropriate action, as viewed by patients
22 and physicians respectively. The tension sometimes led to an implicit dissatisfaction among
23 some patients. We however also observed an offsetting performative potential of numbers,
24 namely that of aligning patients and physicians.

25 **Alignment achieved through the interplay between numbers, physicians and patients**

26 The numbers facilitated the patient-physician dialogue by providing an external abstraction of
27 the illness that was no more the patient's than the physician's. For instance, observations
28 suggested that some patients used numbers to objectify their experience when trying to make
29 the physician aware of a certain health change and convincing the physician about the

1 relevance and ‘truth’ of a certain state or experience. In the following extract, a patient
2 referred to the numerical abstraction of her health in a detached way when suggesting a
3 reduced drug dosage:

4 *I see on the overview I have been able to perform most daily tasks for a long time,*
5 *without problems...this indicates that we could perhaps reduce the drug dosage?*
6 *(Patient to physician- field-notes observing interaction, Observation #3).*

7 The numbers’ assumed objectivity enabled this patient’s communication to remain factual
8 and non-emotional. Patients generally considered this the best way to be taken seriously by
9 the physicians. For instance, a patient expressed how she drew on the authority of her
10 numerical scores to negotiate with her physician and to develop alignment about her needs:

11 *Those numbers, it’s like, it’s not my subjective assessment. It’s not me “winning.” This*
12 *is something I got from the SYSTEM. This is ‘correct’. I think the doctor takes it*
13 *seriously. If my doctor says: this medication is good, I can say, but ...look at the*
14 *scores, they could indeed be better... That provokes my doctor...and that's what I*
15 *want. (Patient #10, Female, 6 years of diagnosis).*

16 Thus some of the patients realised the importance of what numbers were actually displayed,
17 what scores they “got” in the system. While there were patients who did not figure out a way
18 to “use” the numbers to negotiate with their physician, many patients became adept at
19 adjusting and managing their numbers to portray their illness in a way that aligned action
20 with their desired treatment.

21 *At one visit, I got the impression that my doctor concluded that I was very well [based*
22 *on the numbers] while I didn’t feel well at all! ... perhaps as [I was] trying to be*
23 *”modest” and optimistic. So the next time, I was much less...positive. I rated my*
24 *health on the bad end on most dimensions.... This made my doctor look up from the*
25 *computer (Patient #28, Male, 3 years of diagnosis).*

26 By applying numbers in ways that made the numbers reflect “non-measurable” aspects,
27 patients worked around the reducibility of the numbers so as to reframe physician action.

28 Further, physicians could bring alignment between their and the patients view by using the
29 numbers’ objectivity and authority to recommend treatment:

1 *Sometimes my patients question my decisions...why I prescribed a certain drug ...*
2 *Then use the data to show them, [and] suggest 'that the drug you don't want is in fact*
3 *producing changes!' I think this makes my way of reasoning more understandable to*
4 *the patient ...that I am basing my decisions on the data* (Physician #18, Male, 10
5 years of experience).

6 Numbers also facilitated communication when physicians and patients had different ways of
7 producing numerical scores, such as counting the swollen joints. A patient might count a joint
8 'swollen' when in the physicians' estimation, it was not swollen enough to warrant a 'score'.
9 In the following quote a physician explains how the different ways of deriving numbers could
10 trigger a discussion in which the physician explains the 'correct way' of determining
11 inflammation. In so doing the patient learns how the physician, as a professional, thinks and
12 responds to numbers and how to align with this view.

13 *I would perhaps argue that the patient has 3 swollen joints, while she may have*
14 *entered 6. ... It triggers us to talk about how we [specialists] assess joints – ... where*
15 *to press, how to separate swollenness from stiffness. I think it usually leads to a better*
16 *understanding on both sides ...* (Physician #11, Female, 5 years of experience).

18 **DISCUSSION AND CONCLUSION**

19 Our study of how numbers perform in the on-going management of illness makes two
20 contributions. First, as illustrated in Figure 3, we develop new theoretical insight into how
21 numbers perform in the specific setting of microlevel illness management, namely by
22 constructing the disease across time, and by framing action. Given the different perspectives
23 and responses of physicians and patients to the work of numbers, tensions are created as well
24 as new forms of alignment. Second, we contribute to the interdisciplinary literature on
25 performativity, by providing a dynamic understanding of how numbers perform across time
26 at the microlevel. This extends the current more system-level focus of the work of numbers at
27 a set point in time.

28 **The performativity of numbers in illness management**

1 Insert figure 3.

2 Drawing on our empirical findings, we developed a model (see Figure 3) of the process
3 through which numbers participate in illness management over time. Though our analysis
4 focused on the use of numbers in the patient-physician encounter, and thus on their
5 performance in the present, we show how numbers worked to orientate patients and
6 physicians across time. As illustrated above, the numbers enabled some patients to draw on
7 their past experiences and reinterpret them in measureable ways so that the patient's illness
8 could be separated out from their past life. By working to separate a patient's illness and their
9 wider life, the numbers made the patient's disease comparable across time, thereby defining
10 whether or not they were improving. In so doing, patients reduced holistic aspects of their
11 disease to more atomistic perceptions. Nonetheless, patients still wanted to speak about their
12 "overall" feeling, sleep patterns, or other non-measureable dimensions. This contradiction
13 seems to indicate that patients often moved interchangeably between atomistic and holistic
14 perceptions of their illness. On the other hand, for physicians, numbers clarified those patient
15 experiences to which they needed to pay attention, focusing on the atomistic perceptions of
16 disease enabled by the commensurable numbers. Further, numbers directed physicians'
17 attention to the internal consistency of the many dimensions, and worked to predict the future
18 trajectory of the disease.

19 As such numbers tended to enable patients to be orientated to the past, taking account of what
20 had been occurring over the interval since the preceding assessment during their meeting (in
21 the present) with the doctor. Similarly, physicians were able to orientate themselves to the
22 future trajectory of the illness (Strauss et al.,1985). We also suggest that the reducibility and
23 comparability of numbers enabled physicians to connect illness across time by linking them
24 to illness trajectories.

1 Our model shows how numbers frame action, particularly the action of physicians whose
2 attention tended to become focused on what was their responsibility and what course of
3 treatment might change the numbers and make patients better. This can be seen as a
4 disciplinary influence of numbers, which also sets up an implicit causal link between the
5 illness and the current drug treatment while obscuring other links. For example, if the
6 numbers are high, causes were linked to the illness flaring, or the drug not working. Having
7 established a boundary between the disease and the ‘rest of life’, the latter was no longer
8 framed in the ensuing action. The numbers established what could be legitimately acted on,
9 and what was not acted on. Thus, though non-measured aspects like sleep or exercise may
10 influence disease, physicians typically did not frame actions around such activities. Given the
11 limited time available during patient visits, physicians focused their attention on the
12 measureable and tied to medical guidelines. Thus they were surrounded by a degree of
13 assurance about how to act on certain scores and thus “within their professional
14 responsibility”. In this way numbers encouraged physicians to focus on the more atomistic
15 aspects of patient illness. We suspect that this performative tendency of numbers was
16 particularly strong because disease progression and manifestation is generally erratic in
17 rheumatology. Given the ambiguity and uncertainty characterizing their specialty, the
18 delimiting and commensurable nature of numbers enabled physicians to feel and appear “in
19 control” and their object (the disease) as “manageable”.

20 By showing how numbers perform differently for patients and physicians, our model
21 accounts for the dynamic interplay between the performativity of numbers, patients, and
22 physicians, which becomes manifest during patient physician encounters, as shown by the
23 circle with dashed lines in figure 3. For example, tension can arise when numbers frame one
24 action and not another. Similarly, the “objective” comparisons enabled by numbers, may
25 generate alignment as actors communicate via the numbers. Thus the reactivity associated

with the work of numbers (Espeland and Sauder, 2007) can be seen to be linked both to what the numbers themselves are doing, but also to the different possible responses to these numbers. One could imagine for example that patients and physicians might also face an ongoing dynamic based on the possible tensions and alignment that numbers are producing. For instance, numbers can go beyond (mechanistically) pointing to various ‘alternatives’ or ‘choices’ with more or less plausible outcomes, by providing an ongoing and dynamic basis for both patient and physicians to mutually understand each other, express concern and show empathy, and thereby engaging in ‘care practices’ (Mol, 2008). Rather than an agency that stops and starts, the numbers perform in a continuous fashion, for example as tensions are being negotiated to achieve alignment. As such the work of numbers can be revised, and a new score given to one’s level of pain, which can frame new action around the drugs being prescribed, thereby connecting the patient and physician encounter to a new illness management plan and future trajectory.

Towards a dynamic view of performativity

Our model extends several arguments in the interdisciplinary literature on the work of numbers, including the limited work on the performativity of numbers in healthcare. While the extant literature has hereto largely theorised the performativity of numbers at a conceptual, organisational or system-level (Nicholls, 2013; Espeland and Stevens, 1998; 2008; Porter, 1995; Power, 1997; Wallenburg et al. 2016), less attention has been paid to the microlevel performativity of numbers, in relation to different actors, and how different performativities interact across time. Our work lends support to the argument that numerical performativity is tied to the capacity of numbers to commensurate previously non-comparable entities (Espeland and Stevens, 1998; 2008). In accordance with the wider institutional pressures for standardisation in healthcare (Timmermans and Berg, 2003), in our case the numbers were generated about pre-defined areas, thus building on a standardisation

1 of how to document and monitor interventions and their health outcomes. The performativity
2 of the numbers were further shaped by the existence of external, medical standards against
3 which the numbers could be interpreted. In contrast to previous work, which emphasises the
4 tendency of numerical commensuration to push non-measured variation aside, our model
5 suggests that the authority of the numbers is questioned and negotiated, possibly as atomistic
6 or holistic perceptions of the disease are brought to the fore, thus generating a process of
7 illness management in which discretion continuously moves across numbers, patients and
8 physicians. This puts into question the largely static view of numerical authority as
9 dominating in the interdisciplinary literature on the work of numbers, quantification and
10 numerical measurement, epitomised by Porters (1995) seminal argument that trust in numbers
11 tends to replace trust in people.

12 In our case, numbers were often distrusted. Yet, the numbers gained authority as they opened
13 up new possibilities for communication, by providing a shared, language and a “new”
14 resource that both patients and physicians had the right to utilise. They could use this to
15 resolve issues, and align perspectives, thus reducing the knowledge distance between patients
16 and physicians (Porter, 1995). For instance, in guiding (disciplining) patients on how to
17 construct and analyse their disease, the numbers empowered patients by enabling them to
18 communicate on more equal terms with professionals. The patients used numbers and their
19 gradually acquired numeracy like a “currency” that enabled negotiations with the physician.
20 Indeed, numbers worked by enabling patients to play by the rules of the medical game.
21 Notably, the numbers also made patients able to game the rules, by manipulating their scores,
22 for instance.

23 The implication of these insights is the need to study situational responses to the disciplinary
24 potential of numbers (Porter, 1995). In our case, the discipline enforced by numbers had both

1 constraining and enabling effects. The interaction between such constraining and liberating
2 consequences of numerical performativity over time warrants further research.

3 **Practical implications**

4 Our results point at the potential of numbers to shape patients' and physicians' understanding
5 of disease and choice of action, even in cases where they are aware of the limited ability of
6 numbers to accurately describe reality. This generative potential of numbers makes the
7 selection of patient and physician reported measures in health IT systems a critical process in
8 which participants need to consider if and how measures primarily facilitate scientific study,
9 billing, or if the measures are relevant from patients' day-to-day illness management
10 perspective. Involving patients in selecting and continuously revising measures in existing
11 systems is one way to counterbalance the reducing potential of numbers selected primarily on
12 basis of the requirements posed by financial reporting or quantitative scientific study.
13 Conflicts between patients desire for dynamic variables reflecting their individual and
14 variable symptoms on the one hand, and the need for standardised variables required for
15 aggregation purposes on the other hand may here emerge, as observed in our case (Essén and
16 Sauder, 2017). The move towards quantification in society more generally (Espeland and
17 Sauder 2007) may further constrain opportunities for complementing standardised variables
18 with free-text descriptions.

19 The findings also highlight the frail ability of a static set of numbers to accurately and
20 objectively describe the disease in contexts such as rheumatoid arthritis, where there is wide
21 variation in how the disease manifests across patients and over time. This points to further
22 risk associated with uses of such data for purposes of external evaluation and reimbursement.
23 When used as aggregates by external parties, the ambiguity and need to corroborate
24 numerical representations with other forms of knowledge (which is often evident to those

producing the numbers) may get lost.

REFERENCES

- Alvesson, M. 2003. Beyond Neopositivists, Romantics, and Localists: A Reflexive Approach to Interviews in Organizational Research. *Academy of Management Review*. 1, 28, 13-33.
- Callon, M.(ed)1998. *The Laws of the Markets*. Oxford: Blackwell Publishers.
- Corbin, J.M., Strauss, A.L. 2008. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Sage Publications, Inc.
- Crosby, A. W. 1997. *The Measure of Reality: Quantification and Western Society, 1250–1600*. New York, NY: Cambridge University Press.
- Déjean, F., Gond, J.P., Leca, B. 2004. Measuring the Unmeasured: An Institutional Entrepreneur’s Strategy in an Emerging Industry. *Human Relations*. 57: 741–64.
- Espeland W.N., Stevens, M. 1998. Commensuration as a social process. *Annu Rev Sociol* 24: 313-43.
- Espeland, W., Sauder, M. 2007. Rankings and Reactivity: How Public Measures Recreate Social Worlds. *American Journal of Sociology* 113:1-40.
- Espeland, W.N., Stevens, M. 2008. A Sociology of Quantification, *European Journal of Sociology*, 49(3), 401-436.
- Essén, A. Lindblad, S. 2013. Innovation as emergence in healthcare: unpacking change from within. *Social science & medicine* 93, 203-211
- Essén A, Sauder M. 2017. The evolution of weak standards: The case of the Swedish rheumatology quality registry. *Sociol Health Illn*. 2016 Nov 23. doi: 10.1111/1467-9566.12507. [Epub ahead of print]
- Foucault, M. 1977. *Discipline and Punish: The Birth of the Prison*. London, UK: Allen Lane.
- Leca, B., Naccache, P. 2006. A Critical Realist Approach To Institutional Entrepreneurship. *Organization*. Volume 13(5): 627–651.
- Lofland, J., Snow, D., Anderson, L., Lofland, L.H. 2006. *Analyzing Social Settings: A Guide to Qualitative Observation and Analysis*. Canada: Thomson Wadsworth.
- Mol, A.M. 2008. *The logic of care: health and the problem of patient choice*. Abingdon: Routledge.

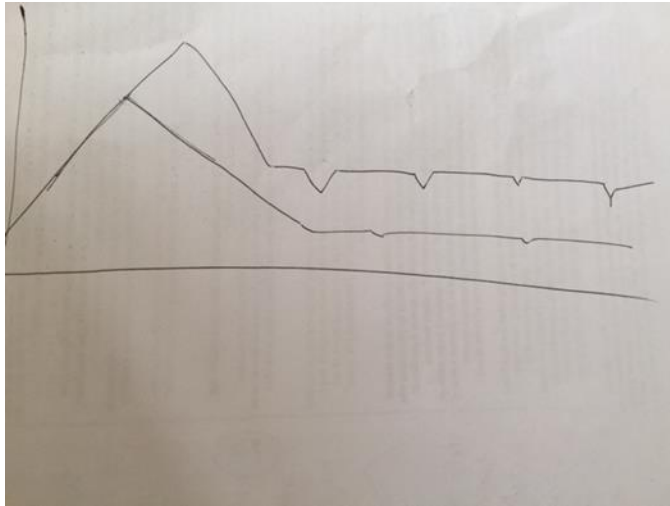
- 1 Nicholls, S. 2013. Standards and classification: A perspective on the 'obesity epidemic',
2 *Social Science & Medicine*, 87, 9-15
- 3 Nussbaum, M. 1986. *The Fragility of Goodness: Luck and Ethics in Greek Tragedy and*
4 *Philosophy*. New York, Cambridge University Press.
- 5 Porter ,T.M. 1995. *Trust in numbers: the pursuit of objectivity in science and daily life*
6 Princeton; Princeton University Press.
- 7 Power, M. 1997. *The Audit Society: Rituals of Verification*. Oxford: Oxford University
8 Press.
- 9 Strauss, A.L., Fagerhaugh, S., Suczek, B. and Wiener, C. 1985. *Social Organisation of*
10 *Medical Work*. Chicago: University of Chicago Press.
- 11 Timmermans M., Berg M 2003 *The Gold Standard*. Tempel University Press.
- 12 Wallenburg, I., Quartz, J. Bal, R. 2016. Making hospitals governable. Performativity and
13 institutional work in ranking practices. *Administration & Society*, Online first, Nov. 1-27.
- 14
- 15 Weber, M. 1978. *Economy and Society: An Outline of Interpretive Sociology*. Berkeley,
16 CA: University of California Press.
- 17
- 18 Wehrens, R.L.E., Bal, R.A. 2012. Health programs struggling with complexity: A case
19 study of the Dutch 'PreCare' project. *Social Science & Medicine*, 75, 274-282.
- 20
- 21 Yin, R.K. 2009. *Case Study Research. Design and Methods*. Sage Publications, Thousand
22 Oaks, 4th ed.
- 23
- 24

Figures and tables

Figures 1-3

Figure 1. The registry numbers as displayed on the physician's screen. Registry data about one fictive patient with a specific RA diagnosis (spondylitis) (in Swedish). Physician reported drug dosages are displayed in rows NSAID, KORT, DMARD. Lab tests include SR, CRP. Patient reported values are displayed in the rows: EQ5D, "Svullna leder" (Join 66/28), "Ömma leder" (Joint 68/28). The DAS28 row is coloured in green (low disease activity), yellow (medium) and red (high) depending on the index score.

Patient		Nytt besök Översikt Skriv ut översikt Visa graf Felrapport Min Sida									
Personnummer	19121212-1212	År	2010	2010	2010	2010	2010	2010	2010	2010	2010
Namn	Tålvan Tålvansson	Dag Månad	05-May	21-May	08-Jun	14-Jun	15-Jun	17-Jun	31-Aug	06-Sep	13-Sep
PAL	Maryam Dastmalchi	Årskontroll									
Tillhörighet	Solna	Månads-Kontroll	77	78	78	79	79	79	81	81	82
TA-patient	Nej	MK-grupp									
Diagnos	ICD 10 Sjukdomsdebut	Arbetsförmåga	40/40	40/40	40/40	40/40	40/40	40/40	40/40	40/40	40/40
Ankyloserande spo...	M45.9 2001-01-01	Allmän hälsa	37	39	64	39	13	29	38	56	36
Behandlingsriktlinjer		SR	12	15	12		23	23	12	56	34
		Läkarbedömning	Låg	Måttlig			Måttlig	Måttlig	Låg	Måttlig	Måttlig
		EQ5D	0.597	0.083	0.096	1	0.597	0.174	0.789	0.666	1
		CRP	<5	5	8		12	12	2	55	12
Patientdata		Spond.artrit, Ank.spond.									
Tidigare medicinering		BASFI				2.1	2.1	2.1			
Kriterier		Svullna leder (66)								6	
Arbetsförmåga		Ömma leder (68)								9	
Händelseboken		Daktylit				Nej	Nej				Ja
EQ-5D		Svullna leder (28)	5	3	1	1	0	3	1	12	3
BASDAI		Ömma leder (28)	3	2	0	0	2	6	3	9	1
BASFI		Entesit				Nej	Ja				Nej
BASMI		Funktionsneds. - HAQ	1	2	2	1		2	1.88	1.63	1
BMI		Smärta	32	52	61	17	45	54	41	5	52
Komorbiditet		TIRA									
Funktional Index 2		Trombocyter									
Grippit		DAS28	3.85	3.72	2.92		3.17	4.46	3.52	6.25	4.02
HAQ		BASDAI		7.2		2.3	9.5	3.4			3.7
Lung-undersökningar		DAS28CRP	3.72	3.43	2.93		2.86	4.15	3.14	5.84	3.43
MAP		NSAID		COX1	COX1	COX1	COX1	COX1	COX1	COX1	COX1
MDAAT		KORT	PRE	PRE	PRE	PRE	PRE	PRE	PRE	PRE	PRE
		KORT dos	20/1d	15/1d	15/1d	15/1d	5/1d	5/1d	5/1d	5/1d	2.5/1d
		DMARD 1	MTX	MTX	MTX	MTX	MTX	MTX			
		DMARD 1 dos	20/1v	15/1v	15/1v	15/1v	20/1v	10/1v			
		DMARD 2									
		DMARD 2 dos									
		DMARD 3									
		DMARD 3 dos									
		DMARD 4									
		DMARD 4 dos									
		Uppföljd månad	0	0	0	0	0		0	0	
		Uppföljt läkemedel	ENB	ENB	ROA	ROA	ROA		ORE	ENB	
		Läkemedelsdos	50/1v	50/1v	480/1m	480/1m	480/1m		750/4v	50/1v	



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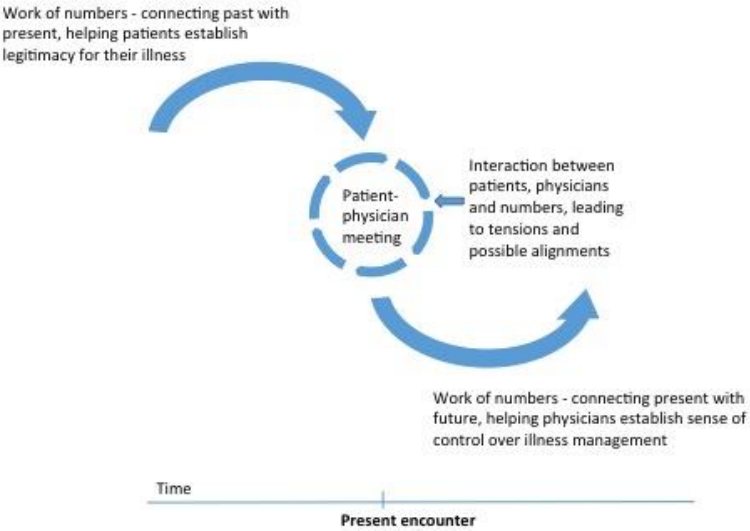
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Figure 2. Possible disease trajectories as illustrated by a physician during an interview.
The physician envisioned the number as a point at this trajectory

Figure 3. A conceptual model of the performativity of numbers in the microlevel management of rheumatoid disease.



1 Tables 1-3

2 Table 1. Sources of empirical data. Collected between 2009-2014.

Sources of material	Details
41 interviews with clinicians.	<p>41 interviews with 39 clinicians using the registry: 34 rheumatologists, 3 nurses, 1 physician's secretary, 1 physical therapist. The first-listed author conducted 21 interviews. A co-researcher involved in the larger registry program conducted the remaining 20 interviews</p> <p>2-22 years of practice experience; 1-16 years of experience of the registry; Age: 40-67 years.</p> <p>Recruiting: All (150) professionals who attended a yearly rheumatology-seminar were asked for an interview. 31 accepted. In order to cover a wider reach of regions and positions, 14 additional members were recruited through the registry administration</p>
10 interviews with members of the registry administration.	<p>10 interviews with 6 registry board members: rheumatologists, patient care designer, nurses, course Administrators, IT-specialist.</p>
32 interviews with patients.	<p>32 interviews with 29 patients. The first-listed author conducted 24 interviews. A co-researcher involved in the larger registry program conducted the remaining 8 interviews.</p> <p>22 (F), 7 (M); Age 33-75 years; No. of years since diagnosis: 1- 25.</p> <p>All but 4 interviews took place face-to-face. For the sake of convenience, the F2F interviews took place in the Stockholm area.</p> <p>Recruiting: via rheumatologists and patient networks.</p>
Observations of 15 patient-physician encounters. .	<p>The first-listed author performed observations (Lofland et al. 2006) of 15 encounters. Each encounter lasted between 10 and 40 minutes; approximately 300 min in total.</p> <p>Age of patients: 40-65 years; 2 (M), 13 (F); No. of years since diagnosis: 4-10; Practitioners: 2 specialists (M) and 1 nurse (F). .</p>
Observations of meetings and seminars.	<p>The first-listed author engaged in informal conversations with practitioners, and attended formal and informal meetings (N=82) (participant observations), e.g. meetings held by the SRR ((Swedish Society of Rheumatologists), the QR board, workshops/seminars at Karolinska Institutet and QR meetings hosted by governmental agencies)) where rheumatologist practice and the registry were discussed during 2009-2014 period.</p>
Documents.	<p>National guidelines for rheumatology/internal diseases, registry annual reports, registry steering meeting protocols, and articles in trade/daily press about the registry/PER 2000-2014 were gathered.</p>

3

4

Table 2. Simplified overview of the coding process. In an iterative fashion, open codes were clustered into themes, which were theorized into categories of numerical performances.

